Submission to Committee on the Rights of Persons with Disabilities on the Draft General Comment on Article 12

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The draft comment[1] is very helpful in clarifying a number of important points. The statements concerning the distinction between legal capacity and mental capacity (paragraphs 9 and 12), the essential requirements for, and the organisation of, supported decision-making (paragraphs 14-18), and the central importance of the person's 'will and preferences' (paragraphs 15, 22, 23, 25) are clearly spelt out.

An important area is not sufficiently addressed: the meaning of 'will and preferences'

There remains, however, an important gap in the discussion of the overall conceptual structure underlying Article 12. This concerns the meaning of *'will and preferences'* in relation to legal capacity and, crucially, its connection with what might constitute 'substitute decision-making'. Despite its prominence in the draft comments insisting that a person's will and preferences must be respected, I find no discussion on how 'will and preferences' is to be interpreted. This aspect is of particular relevance to persons who are treated within the psychiatric system, though it is also relevant to all persons where a difficulty arises in determining what a person's 'will and preferences' are. It is also a problem when the current 'will and preferences' expressed by a person are different to those expressed previously, particularly when those have been long-lasting and have had a large influence on the way the person has chosen to live their life. What should be taken as the person's will and preferences under the terms of the Convention?

I entirely agree with the Committee's view (paragraph 13) that an impairment of mental capacity does not justify any restriction of a person's legal capacity - that is, an impairment of decision-making capability *on its own* would not do so. If an impairment of decision-making capability is to play a role in affecting legal capacity, more is required. In legislation like the Mental Capacity Act 2005 in England there is a further requirement that the intervention should be in the person's 'best interests' - a controversial notion, but one capable of transformation, I will suggest, as guided by the terms of the Convention.

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[1] Committee on the Rights of Persons with Disabilities (2013) General comment on Article 12: Equal recognition before the law. UN CRPD/C/11/4

Any law relating to impaired decision-making must be generic

Conventional mental health laws, dependent as they are on a 'status' criterion (such as requiring the presence of a 'mental disorder', that is, a category of persons with a particular kind of disability) discriminate against the group of persons who are thus singled out. If 'mental disorder' is a necessary criterion, no matter how many additional criteria may be required, such a law can be seen as discriminatory. Whatever law might apply in the case of persons who appear to have a significant problem with decision-making *must apply equally to everyone*, not selectively to a group defined by a disability. Such law must be generic. My colleagues and I have argued this for some time[2,3].

Meaning of 'substitute decision-making'

The case is made that 'substitute decision-making' as defined in paragraph 23 is not consistent with Article 12. Especially noteworthy here is that element of its characterisation as follows:

> *"(iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences."*

The 'objective best interests' test is not consistent with the central idea of the person's 'will and preferences' (though they may, of course, coincide). But what if the 'substitute decision', perhaps better termed the 'substitute judgement', were based squarely on the person's own 'will and preferences'? Would that be consistent with Article 12? There are some obvious ways in which this might occur; for example, if the person were to make an *advance statement*, when having decision-making capability, anticipating a time when decision-making capability will be impaired, and which indicated clearly the person's preferences - whether highly specific, or by stating the values that should guide any decision about treatment. If the person, having lost their decision-making capability, as predicted and in the circumstances foreseen, were at that time to reject the treatment they had indicated they preferred, would its imposition as an 'involuntary' patient be justified under the CRPD?

Some situations requiring further attention

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[2] Dawson J, Szmukler G. Fusion of mental health and incapacity legislation. *Br J Psychiatry*. 2006;188:504-509.

[3] Szmukler G, Daw R, Callard F. Mental health law and the UN Convention on the Rights of Persons with Disabilities. *International Journal of Law and Psychiatry*. 2013 http://dx.doi.org/10.1016/j.ijlp.2013.11.024 [Epub ahead of print]

What about the situation where there is no advance statement, and a person is rejecting treatment in circumstances where there appears to be a problem with decision-making capability, and a decision having serious consequences for the person needs to be made? What the person's 'will and preferences' might be would surely be a critical question that needs to be to be addressed. Are the current preferences expressed in the rejection of treatment consistent with the person's 'enduring' preferences (as manifest in his or her previous life choices)? If not, is there good reason to conclude that they are, or are not, what could be considered the person's '*authentic'* preferences?

Consider two vignettes:

1 A middle-aged man consents competently to a serious, but life-saving operation. Post-operatively, as a result of the metabolic changes associated with the surgery and an infection, he becomes confused, and fears he is the subject of illegal experimentation in prison laboratory, pulls out his intravenous drip - essential to maintain metabolic stability and to administer an antibiotic - and attempts to leave the ward. If allowed to carry on in this manner, he will collapse and probably die. All attempts at supportive decision-making fail. The clinicians in conjunction with the patient's supporters agree that his 'authentic' 'will and preferences' are to continue to live – that was why he agreed to the operation - and that restraint and 'involuntary' treatment is justified.

2 A middle-aged man, for the first time in his life, has a major change in his personality. Over a period of a month - he becomes extremely elated in mood; feels exceptionally confident in his abilities; is easily irritated with others who doubt his 'special talents'; has racing thoughts and that are often jumbled, particularly when serious matters are raised; he is extremely distractible and is unable to keep to the subject of a conversation for more than a minute; he starts to invest huge proportion of his money in shares that are considered extremely high-risk, unshakeably confident in his new-found powers of prediction; he becomes sexually disinhibited and has, for the first time ever, liaisons with a series of prostitutes, exploits he recounts to his wife with glee and sarcasm; to the chagrin of his employers, he leaves work after an hour claiming that one hour of his brilliance is equivalent to a day's work by the others. Prior to this he was a man of moderate habits, prudent with money, a careful planner, a conscientious worker and one who valued family life virtually above all else. Despite much support from his wife, his parents and his best friend he refuses to see the family doctor for an assessment. He says his previous life was a 'sham'; now he knows who he 'really is'. Which, then, are his 'authentic' will and preferences – those that are current or those that seem to have guided his life choices up to the previous month? If they are the latter, then 'involuntary' treatment would be consistent with the significance given in the Convention to the respect to be given to a person's 'will and preferences'.

Sometimes determining what the person's will and preferences are will be very challenging and depend on some form of 'interpretation'[4,5]. But I don't think the attempt can be avoided given, correctly in my view, its prominence in the Convention.

The argument would be that facilitating expression of a person's 'authentic' will and preferences, when the person cannot do so at a particular time because of some kind of problem, including illness, is not a form of 'substitute decision making' but supports that person's standing. Safeguards are, of course necessary, perhaps along the lines of Art. 12(4). In one sense such an intervention is 'involuntary', in another sense that doesn't seem to be quite the right description. Whatever one calls it, it respects the person. Would it be showing respect for the dignity of the persons in the vignettes above, to allow the first to die and the second to devastate his own and his family's futures?

It might be pointed out that the man in the first vignette might not be regarded as having a disability – the impairment is not 'long-term'. However, the same issues of will and preferences would apply in the same post-operative situation if the man were someone with an intellectual disability who, with support, had decided to have the operation. Indeed, both patients, the one with and the one without a disability, would thus be treated on an equal basis.

Implications

If the propositions above have validity, the statement in paragraph 36:

> *Respecting the right to legal capacity of persons with disabilities on an equal basis includes respecting the right of persons with disabilities to liberty and security of the person. The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is an ongoing problem. This practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention.*

would require some modification, as would paragraph 38:

> *As has been stated in several concluding observations, forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17), freedom from torture (art. 15), and freedom from violence, exploitation and*

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[4] Banner N & Szmukler G. 'Radical interpretation' and the assessment of decision-making capacity. *Journal of Applied Philosophy* 30:379-394, 2013 (available online: http://onlinelibrary.wiley.com/doi/10.1111/japp.12035/abstract)

[5] Bach M & Kerzner L.. *A new paradigm for protecting autonomy and the right to legal capacity.* Law Commission of Ontario. 2010. http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner

> *abuse (art. 16). This practice denies the legal capacity of a person to choose medical treatment and is therefore a violation of article 12 of the Convention. ……. . States must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation of mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness[6] and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment. The Committee recommends that State parties ensure that decisions relating to a person's physical or mental integrity can only be taken with the free and informed consent of the person concerned.*

These paragraphs can be read as denying there is any situation at all that under the terms of the Convention could warrant involuntary treatment. If that is the intention, this goes against a widely held moral intuition that sometimes others ought to step in when a person who is clearly unable to make a judgement about their predicament is faced with a serious threat to his or her well-being. The analysis I have offered above would make such a reading unacceptable.

There is no doubt that there have been, and still are, many serious abuses of involuntary treatment. The Convention provides a sound basis for condemning and remedying these. It is also true that involuntary treatment is often extremely humiliating and distressing. But again, provisions for support and respect for persons' 'will and preferences' as expressed in the Convention could go a long way to providing a framework for empowering those with mental health problems and improving their lives very substantially.

[6] This is a bold statement that should be supported by references to the evidence.